

Essay

Banking on Participation: Exploring the Co-production of Population and Public in Swiss Biobanking

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Abstract: This paper explores enactments of participation in two Swiss biobanking configurations, a cohort biobank and a general biobank. It sheds light on the role of Personalized Health endeavours, in which biobanks play a crucial role. In order to contribute to the understanding of the role of participation in biomedical research dynamics, the analysis focuses on the processes of co-production of identity and biobanks (Tupasela et al. 2015). It documents the overlaps between the *population* – providers of biological samples – and the *public*, the collective who is expected to give its opinion on issues raised by the reconfiguration of the research/healthcare interface. It shows that modalities of participation impact the potential scientific value derived from the biobank's population, but also that the reconfiguration of the research/healthcare interface at the core of biobanking contributes to the current blooming of discourses and practices of participation. It argues that the forms of collective identity shaped through participation as *population* and/or *public*, exceed formal strategies of participatory governance and may play an even more important role in the shaping of biobanking configurations.

Keywords: biobanks; public participation; biosociality; personalized health; genomic research.

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1. Introduction

“Nowadays we do not do research *on* patients any more, but *with* patients,” said the Dean of the Faculty of Medicine at a medical conference organized by the cantonal University Hospital on the theme of clinical

research, which featured a local cohort study as its hallmark (Public Event 08/06/2017). He explained this transformation by some infamous public scandals generated by the mistreatment and exploitation of patients enrolled in medical experiments. “Now we need to hear them, to take their voice and their families into account,” he added. In this way, he stressed how they had impacted the patient’s status in relation to the traditional authority and paternalistic attitude of doctors, not only in clinical settings, but also in research. No more passive subjects, taking risks for the sake of medical progress, sometimes without their knowledge, the new figure of the patient he alluded to was that of a well-informed research participant, whose opinions and personal situation would from now on be taken into account.

In contrast with this ideal figure, in Switzerland, patients’ voice does usually not appear prominently in the debates around biomedical research and they are not engaged in the new forms of participatory governance which flourish in neighbouring EU countries in the “politics of life”, comprising controversial new biotechnologies or entities challenging social and cultural understandings of what “life” is, such as genetic testing, GMO, or human embryonic stem cells (Gottweis 2008). The country has so far rather been characterized by the frailty of patients’ social movements and the absence of so-called ‘public participation’ initiatives in relation to biomedical research¹. However, calls for doing “research *with* patients” have recently started to be voiced in the Swiss landscape in the specific context of “Personalized Health” (hereafter PH). Used along with other similar terms such as “personalized medicine”, “precision medicine” or “predictive medicine” (see, for example, Redekop and Mladsi 2013), PH is used in Switzerland to designate the broad and rapidly advancing field of biomedical research and healthcare which draws on the combined advances in the field of big data analytics and genomics. Characterizing the move to a data-driven paradigm of biomedical research and healthcare, it aims at improving prevention and treatment interventions according to the personal characteristics of individuals (Meier-Abt and Egli 2016). Biobanks play a crucial role in PH endeavours. Indeed, they are sites where tissues from which genomic data are collected, analyzed, and correlated with other health-related data, are stored, preserved and made available for researchers. Due to the need to preserve some connection between biosamples, data and the individuals they come from, they have raised issues debated internationally, especially around consent, incidental findings and the return of individual research results (Neresini and Viteritti 2014; Wadman and Hoeyer 2014; Hogle 2016; Tupasela et al. 2017).

While most experts in Switzerland agree that the scope of societal, ethical and political issues raised by PH and its associated biobanking is such that a public debate and participatory procedures would be needed, most strategic decisions have been taken by experts and there has not been any public controversy on the subject yet. However, at a local level,

2017 marked the emergence, at a local level, of institutional demands for “public participation” in the governance of biobanking, along with a growing number of research projects in medical and social sciences engaging with the ‘societal’ aspects of PH, as illustrated by the launch of the “Personalized Health & Society Initiative”² by a nonprofit foundation. How can we explain the current emergence of demands for ‘public participation’ and the sudden importance of lay opinion in experts’ discourses in the domain of PH? What kinds of factors contribute to the rapid transformation of experts’ view of participation in biobanking, from a relatively unproblematic act, restricted to hospital-based biomedical research – providing biological samples – to a societal matter, worthy of a wide social debate? Finally, what is participation in these emergent discourses and practices and how is it shaped?

In order to unpack the notion of participation and contribute to the understanding of the role it plays in biomedical research dynamics, we draw on the argument made by Tupasela et al. (2015) that biobanking configurations and identity are co-produced, meaning that people participating in biobanking by providing samples and/or giving their opinion, and from which biobanks draw their legitimacy, contribute to define the characteristics and identity of biobanks, as much as those shape the identity of the collectives that they study and/or engage with. This allows us to understand how the collectives involved in biobanking shape their configuration as much as biobanking generates new forms of collective identity or biosociality (Rabinow 2008; Gibbon and Novas 2007). In order to understand these processes, we need first to situate them in the context of PH endeavours in Switzerland. Our analysis will then turn to two biobanking configurations and their enactments of participation: 1) a cohort biobank, and 2) a general biobank which are based in the same Canton. Focusing on the perspective of experts engaged in PH – biobankers, researchers and clinicians – we will show that while, in the promissory discourses of PH advocates, all Swiss citizens might turn their daily lives into a reservoir for data production for the stake of research, blurring in this way the boundary between research and healthcare, in biobanking practices, this boundary is very present. We will show how its reconfiguration is entangled with how participation is framed and may both facilitate and hinder the production of scientific and health values resulting from the collection, storage and use of human biological samples for biomedical research.

2. Between Public and Population: Biobanks and the Co-construction of Identities

While the collection, storage and use of human biological samples for biomedical research is not new, during the last decade, biobanks have gained political and public importance due to the crucial role they play in

the knowledge-based bioeconomy by transforming waste tissues into valuable goods and a source of commercial, scientific, political and social values (Tutton and Corrigan 2004; Mitchell and Waldby 2010; Tupasela 2011). The productivity of biological material in terms of scientific, health and financial value has been conceptualized in terms of ‘bio-value’ to refer “to the yield of both vitality and profitability produced by the biotechnical reformulation of living processes” (Mitchell and Waldby 2010, 336). However, bio-value is not intrinsic in samples themselves and depends on “the various socio-technical arrangements as well as the continuous intellectual affective and technological work of human and non-human actors” (Timmons and Vezyridis 2017, 1243).

Needless to say, biobanks depend very fundamentally on individuals supplying them with health-related data and biological samples – blood, urine and tissues. The role of these bioproviders is all the more crucial insofar as biobanks need a critical mass of data and therefore large population sets, in order to gain statistical power, produce solid scientific knowledge and possibly develop new treatments and prevention strategies. However, people contributing to biobanking are much more than bioproviders, as the literature exploring the political, ethical and social interplay between biobanks and their participants has demonstrated. Two strands of analysis can be identified. Firstly, literature documenting and discussing the growing role and changing status of biobanking’s *public* in terms of governance. The term “public” is used here to connote the “political body of people which is engaged with [it]” (Tupasela et al. 2015, 4). Secondly, literature analysing the politics of identity and community at stake in the constitution of the *population* recruited for biobanking and defined as the “collection of individuals which are studied and acted upon scientifically and medically” (Tupasela et al. 2015, 4).

While it is rooted in the long history of public health policy, the participation of lay experts – citizens, patients and other stakeholders – in the governance of science and technology took a novel turn in the EU in 1990 (Gottweiss 2008). Developed in response to the legitimacy crisis and critique of a democratic deficit, principles of openness, dialogue and transparency, as well as public participation strategies, have increasingly become central issues in the governance of scientific research (Levidow and Marris 2001). As a political and institutional response to public concerns and ambivalence towards science and expertise (Tutton 2007), these strategies have flourished in the last decade, particularly in relation to genomic research and biobanking. This is due, among others, to the many ethical, legal and social issues they raise. Specific topics have especially been put forward, such as the management of consent, data protection, incidental findings and the return of research results (Tutton 2004; Tutton and Corrigan 2004; Gottweiss and Petersen 2008; Kaye and Stranger 2009; Solbakk et al. 2009; O’Doherty and Hawkins 2010). Increasingly formalized and institutionalized, public participation strategies aiming at fostering trust and allegiance among their participants, have thus become

key to their success, legitimacy and long-term sustainability (Welsh and Wynne 2013).

The role of patients' associations in transforming the relationship between researchers and patients or research participants towards more inclusive and symmetrical approaches has been widely recognized in the context of medical research and especially in genetics (Kaufman 2004; Rabeharisoa 2006; Epstein 2008). Inspired by these democratic forms of scientific knowledge production, STS scholars have supported public participation principles and strategies for opening up the possibilities of subverting the epistemological, political and practical hierarchical division between lay and expert knowledge and for broadening the number of political subjects considered relevant, to be included in debates and deliberations (Levidow and Marris 2001; Joly and Kaufmann 2008; Gaskell et al. 2013; Burgess 2014). However, empirical studies show that practices are more contrasted. In the context of biobanking especially, the ambiguity and ambivalence of public engagement strategies in reproducing the same mechanisms which motivated their implementation in the first place is highly discussed (i.e. Wynne 2007; Voss and Amelung 2016). The role they play in silencing dissident voices, and controlling opposition groups and uninvited or "unruly public" (De Saille 2015; Hess 2015) is given particular emphasis. In addition, their legitimating role in gaining public support without questioning the neoliberal ideology of progress underlying the dynamics of scientific innovation has been criticized (Busby 2004; MacNamara and Petersen 2008).

In parallel, a second strand of scholarship has explored more specifically the role played by biobanking configurations, especially large national biobanks, in constituting different forms of subjective and collective identity through the constitution of their *population*. Biobanks often appeal to a rhetoric of identity and to notions of 'authentic' or 'indigenous' anchored in a past of shared national history (Tupasela and Snell 2012; see also Kowal 2013). Genetics, which "plays an important role in stabilizing categories of origin" (Tupasela and Tamminen 2015, 415) is especially salient in their constitution. This contributes to defining the collective identity of their participants in interplay with the genetic, historical, social and political characteristics they are supposed to share initially, and might result in "population branding" (Tupasela 2017) or in "racialized notions of populations" (Reardon and TallBear 2012).

Highlighting the national characteristics of biobanking participants might be used to promote research in a national scientific market driven by competitiveness and technological innovation (Tupasela and Snell 2012; Tutton and Prainsack 2011; Busby and Martin 2006). As a result, it shadows the private and international networks necessary for biomedical research (Busby and Martin 2006; Hauskeller and Beltrame 2016) and transforms the population contributing to the biobank's collection into a form of national capital and reservoir from which commercial value can be derived (Mitchell and Waldby 2010).

Tupasela et al. (2015) have analyzed the construction of the population identity in a dynamic way through their emphasis on co-construction. This term is used to designate the processes “whereby the population from which the biobank draws from, helps to define and characterize the biobank”, and inversely, those through which “identification, collection and distribution of samples and data [...] give rise to the construction of a population at the same time” (2015, 2). They argue that this co-construction process may lead to the bio-objectification of the population. This concept is used to refer to “the way in which life is *made an object* in different settings” (Webster 2012, 3, my emphasis). Initially, it designated the biological entities that are technologically transformed, blur boundaries, become sites of capitalization and raise ethical, legal, political and social issues, such as Umbilical Blood Cord (UCB) (Beltrame 2014; Brown and Williams 2015) or synthetic biology (Dabrock et al. 2013). In a broader sense, it means that participation in biobanking as *population* might lead to a form of reification, essentialization or financial exploitation. In other words, the collective of bioproviders feeding the biobank in data and biological samples might be reduced to a life form abstracted from its broader, social, economic and political context.

In contrast with the population’s collective identity constructed by biobank operators and researchers, and serving above all the production of biovalue, one can ask whether other forms of identity might emerge from the constitution of the “public” engaged with a specific disease, patients’ rights or biobanking governance. Indeed, participation as *public* is supposed to add social value to the pure provision of samples, and is sustained by a democratic ideal, which could provide a space for the critique of the capitalization of the biotech industry (Tutton 2004) and for alternative forms of reciprocity between researchers and samples donors (Busby 2004).

Literature on identity construction of the public recalls us that the implementation of governance strategies might contribute to a form of bio-objectification, as much as the identity construction of the population does, especially when it is used to legitimate biobanking practices without engaging in a meaningful two-way dialogue. A nagging question is whether it might also lead to new forms of collective identity that could be described as biosociality, scientific citizenship or civic agency (Weldon 2004). The concept of biosociality initially coined by Rabinow (2008) refers to collective identities forming around biomedical knowledge, biological entities, and associated institutions (Gibbon and Novas 2007) and is used to describe the process of identity production in active participation from lay experts themselves. It is not possible to refer to an active form of biosociality construction when the terms and agenda of public participation are already fixed and that lay experts have no room to influence wider issues (Weldon 2004; MacNamara and Peterson 2008). However, caring relationships and mutual understanding between lay experts and biobanking experts might also open up some possibility for more active

forms of civic engagement and practical reciprocity (Busby 2004; Weldon 2004).

Our article contributes empirically to the exploration of these questions by focusing on the co-production dynamics of identity between biobanking and its participants in the context of PH endeavours in Switzerland. The distinction between *public*, as the political body of lay people which are consulted to give their opinion or who are engaged in the governance of biobanks, and *population*, as the collective of bioproviders from which biological samples and health-related data are taken, about which biomedical research is done, and to which possible research results might be returned, is analytically useful. However, we want to show that in practice, this distinction is not so clear and is rather the object of constant overlaps and shifts. In particular, we want to shed light on the overlap and shift between *public* and *population* in participation enactments and show how, more than formal public participation strategies, which are considered as time- and resource-consuming activity, the collective identity produced through participation is valued by some experts. This additional collective value legitimizes their research enterprise, preserve its autonomy and provide them with the feeling of caring for their participants, but might also open up a space for the agency of participants which does not seem incompatible with the goals of biobanking.

3. Methods

The data presented in this article were collected as part of a research project commissioned by the Public Health service of Vaud Canton. It consists of two successive parts: 1) a qualitative study investigating local stakeholders' views of an hospital-based biobank and the development of personalized medicine in Vaud Canton (2014-2015); and 2) a qualitative, empirically grounded research project exploring stakeholders' views of PH, focusing especially on the issues it raises for public health and on public engagement, combined with the development of several collaborative initiatives around public engagement (2017-2018). These two long-term studies used a combination of methodologies, including semi-structured interviews, focus groups, observations at conferences and other events associated with PH, and qualitative and quantitative surveys. This article focuses on data collected since the beginning of 2017 on the views of medical and scientific experts involved at various levels in the field of PH on participation in the context of PH and biobanking, including 10 semi-directed, transcribed, interviews with researchers, clinicians and biobankers, and 6 with cantonal lead physicians, as well as ethnographic observations taken at about 20 workshops, conferences, round tables and meetings organized around PH, such as the Swiss Salon Planète Santé³, or events organized by the Leenaards *Personalized Health and Society* initiative⁴.

The two biobanking configurations we explore in this paper were chosen because they are emblematic of the current shift in biobanking we can observe in Switzerland. The first illustrates biobanking based on more traditional epidemiological research, starting to integrate genomics and turning towards a PH approach, but not driven by it. The second one is thought of from the outset as a tool at the service of PH research and inscribed in a data-driven paradigm. It is not focused on specific diseases like the first one, but collects data and biological samples for various prospective research purposes. Moreover, they are situated in the same canton and a similar network of actors revolve around them. While it would be interesting and relevant to document the perspective of participants in biobanking, this paper focuses rather the perspective of scientific and medical experts. It explores their vision of participation in order to highlight how the choices they make and the challenges they meet in terms of infrastructure and organization impact on participation enactments.

4. Personalized Health Made in Switzerland

Motivated by the potential of an ever-growing number of health-related data – genomics and other -omics, medical, and self-tracked – which could be exploited for the benefit of medicine and health promotion thanks to advances in big data technology and analytics, several initiatives were recently introduced in Switzerland. The two most prominent ones are the CHF 68 million⁵ “Swiss Personalized Health Network”⁶ (SPHN) and *Health 2030*⁷, both launched in 2016. They aim at implementing the infrastructure needed to use a massive amount of data for the ‘personalization’ of healthcare and to promote PH.

Biobanks, as sites where biological samples such as blood, human tissues, or DNA are stored for the use of research, have become key sites at the core of PH transformations. In Switzerland, there is no national biobank and until recently, most biobanks were of small size. Based in university hospital services, they could be viewed as unproblematic infrastructural tools serving specific research projects. It is only in the context of PH developments that biobanking has gained in public visibility and has become a political and technological instrument for the promotion of research and innovation. In 2016, notably, the Swiss National Science Foundation (SNSF) started funding a Swiss Biobanking Platform⁸ working towards the standardization of biobanking governance and practices related to the collection, conservation and use of biosamples. Focusing on the improvement of health strategies and the detection of diseases at a very early stage, the financial efforts of these initiatives are justified by the benefit for the health of the population as a whole a data-driven optimization of healthcare is expected to bring (Meier-Abt and Egli 2016).

4.1 Personalized Health – Participative Medicine?

The idea that tomorrow's medicine will be not only be predictive, but also participative, is very present in the discourse of PH advocates⁹. The scope of the transformations brought by the prospect of PH is potentially such that many societal, legal, and ethical challenges – for example data protection, the costs of the healthcare system or the lack of public understanding of genomics – are identified by experts as exceeding their field of expertise. Opening up a public debate is seen by them as a way of engaging people in the PH project, and of gaining their trust and support. “It will work better if they are active and not passive” expressed a genomic researcher and one of the PH advocates who is very committed institutionally and scientifically, as well as vocal in the debates (Researcher 1, workshop 20/02/2017). As a result, emerges from these discourses a figure of an imagined “participatory subject”, that is a person from whom responses to the multiple societal issues raised by PH are expected:

There is no easy answer, and it depends on individuals. Everybody has something to say and we need to put the questions on the table from the very beginning, to bring them to the streets. It concerns all of us, we need to pass the message that YOUR ideas are important, that YOU have something smart to say, and that people start thinking about all this (Researcher 1, workshop 20/02/2017).

The distinction between “public” and “population”, that is between the collective, who is expected to give its opinion on issues raised by PH, and the one which provides samples and data, is conflated in these discourses. The participatory subject of PH is imagined as both an individual who participates in PH by providing data and biological samples, and somebody who gives its opinion and joins in the public debate, the participation as public being supposed to increase the size of the population, in a kind of virtuous circle based on trust and valorisation of the common good. The importance of the common good underlying the social contract at the core of participation in PH can be read in the following quote: “When it comes to data protection, citizens have the right to be protected, but in exchange they have the responsibility of donating their data for the benefit of the common good” (Researcher 1, interview 20.03.2017). In order to contrast this idealized vision of a responsible and active citizen, we now turn to two biobanking configurations in order to document the visions and challenges of researchers and biobankers and highlight how participation is enacted, not only in discourses, but also in practices.

5. Two Biobanking Configurations: The Cohort Biobank and the General Biobank

The first biobanking configuration has emerged in the context of a longitudinal, observational population study aimed at assessing the prevalence of cardiovascular and psychiatric disorders, and identifying their phenotypical, molecular and genetic determinants. The biobank in this configuration is considered as a tool at the service of the cohort study and not as a prominent element that is publicly visible *per se*. The recruitment of the cohort drew on the registers of the City Residents' Office and a first selection was made randomly in order to represent the population of the city between age 35 and 78. While the project was initially funded by a pharmaceutical company, public funding has since taken over. Over time, the original project has expanded into a variety of sub-projects exploring the association of the disorders studied with specific related aspects of health, such as sleep, exercise, pollution or noise. Presenting the study at a conference, one of the researchers at the head of the cohort explained the procedure the study participants go through. After giving their informed consent, which is specific to the study, they undergo a series of physical tests (for example, weight and blood pressure), and respond to an extensive questionnaire of over 900 questions detailing their lifestyle, state of health, and personal history. In addition, they have a blood sample taken and 40 biological markers are tested, in addition to genetic markers. Blood samples and data are securely stored in the cohort's biobank. The data are analysed through Genome Wide Associations¹⁰ (Researcher 2, public event 8/02/2017). Participating in this study as a population requires thus an important "clinical labour", defined by Mitchell and Waldby (2010, 334) as "the regularized, embodied work that members of the national population are expected to perform in their role as biobank participants". This comprises the bodily and mental efforts demanded freely to participants by the various medical examinations, analyses, interviews, trips and other organizational tasks necessary to the realization of medical research.

Opened in January 2013, the second biobanking configuration represents a first attempt, in Switzerland, at systematically collecting bio-material and health-related data from hospital inpatients. In contrast with the cohort biobank, which is built around a specific research project, this general biobank emerged as a primary goal in itself, prevailing over future PH research projects, which had yet to be defined. It was therefore not organized around research into a specific health disorder, and a broad consent was developed in order to address the specific needs of this hospital-based cohort. Unlike the collection of data characterizing the first biobanking configuration, very little is demanded from inpatients in terms of clinical labour and only an additional blood sample is taken, and stored for further biological and genomic analyses, in addition to health-related data taken from medical files.

A special team of recruiters was created in order to inform patients and ask for their consent to contribute to the collection of samples for the biobank. They visited the various medical services, providing patients with information about the biobank's objectives and asking them to sign a broad consent. While the hospital-based biobank was heralded with great promise at the point of its creation (Dessibourg 2012), at the beginning of 2017, it appeared rather as a disappointing enterprise. With 25,721 patients (Bochud et al. 2017), the biobank had almost reached the symbolic threshold of 30,000 biosamples, which was presented as its objective from the very beginning (Nicollier 2014), but no research project had been developed to use them for a long time. It is only in 2018 that a precision medicine unit was created at the University Hospital and that its research team obtained funding for a project exploiting the data and samples of the hospital-based biobank. Moreover, the role, objectives and activity of the biobank remain unclear or even unknown to many health professionals who are not involved in PH developments, as well as to the general population (Biobanker 3, interview 14/03/2017).

6. Constituting a Population: A Matter of Quantity or Quality?

When we started our research, the cohort biobank was often presented to us as an example of both successful research and participation in the sense of a sustained enrolment of the population in the cohort. As the description above indicates, participation in this study as a population requires a significant level of clinical labour and a long-term involvement. However, as one of the researchers of the project told us, the participation rate has remained high and participants are willing to take part in associated subprojects, even though these require them to carry potentially invasive sleep-monitoring devices or geolocalisation trackers (Researcher 2, interview 09.02.2017). Our interlocutor explained the motivation to participate based on two main elements. The first concerns the direct health benefits and care participants may derive from the medical investigations they undergo for research. While the medical examinations provide data, which will be analyzed and might lead subsequently to potential future clinical and preventive applications, they also provide cohort participants with direct information about their health in the present, for example about their blood pressure or sleep apnoea. In this way, the research examinations are presented as a form of medical check-up, whose results are shared with the people enrolled in the cohort and their general practitioners. In addition to the somatic investigation and the direct health value it might bring, the care relationship between the research team and the cohort participants is also presented as a way of maintaining the enrolment of those involved in the study over the long term. According to the researchers, this relationship is characterized by the way the

participants are welcomed and the time spent in interviews. It was presented with pride as a way of giving something back for the sustained engagement of the population. The fact that some people came back from abroad especially for a subsequent phase of the project provided the evidence of the success of this form of personalized care towards research participants, the researcher added (Researcher 2, interview 09.02.2017). The idea that the study allowed people “to learn things about themselves” was fostered publicly by a cohort participant reinforcing the narrative of a population receiving as much as giving (Cohort participant, public event 6/06/2017).

6.1 The City Population, the Cohort Population?

The cohort is named after the city where the research takes place, but also from which its participants come from, as a recruitment criteria was that they were residents of the city. The local dimension of the cohort was particularly highlighted by researchers: “people are proud of being a member of the city cohort” (Researcher 2, interview 09.02.2017). Researchers did not appeal to genetic relatedness or a shared past history to characterize the identity of the cohort’s population, but rather to the city itself. Participating in the cohort is seen by experts as acting as a good citizen of the city, contributing with other residents to a collective enterprise which surpasses their individual benefits, creating a sense of belonging and shared identity which maintains the high and sustained level of participation over the long term. The figure of the participant which emerges from the researchers’ discourses is thus that of a city resident, ready to engage in clinical labour for the future benefit of their city, and who in return, gets an immediate benefit for their own health, care, and the gratification of contributing to a collective enterprise.

As in other genomic research biobanks, a logic of accumulation drives the objectives of the cohort biobank. However, the principle according to which more is best is not enacted in this configuration and the modalities of research participation contribute to the productivity of samples, by improving their quality: “Ideally, in research, one needs a lot of data, and with a very good phenotype, but what made the success of the cohort, is that we are not very big, but we have a very dense phenotype. This is our strength” (Researcher 2, interview 09.02.2017). According to their perspective, the sense of community, created through the participation of the population, plays therefore also a role in the production of scientific and health values, by contributing to increase the quality of health-related data. In order to refine correlations and produce biomedical knowledge, the quality of data matters more than its quantity in this configuration, and the population’s cohort can itself be seen as a technology through which good quality data can be cultivated. However, the restricted size of the population is also a limitation: “The problem for us is size, i.e. statistical power. If we focus on rare mutations or uncommon variants, when we

only have 6,700 participants, we encounter a problem of statistical power” (Researcher 2, interview 09.02.2017). Therefore, the constitution of the cohort through the administrative and geographical unit and social image of the city constitutes both its strength and its limitation in terms of scientific value production.

In contrast, the general biobanking configuration does not constitute its population through long-term participation in the study. As the required clinical labour is minimal and there is no specific disease defining the goal of biomedical research based on the samples provided, the population remains without a well-defined identity. Inpatients are rather thought of as bioproviders and their potentially increasing number seen as an asset. Indeed, this biobank is configured as a tool for biomedical research whose potential for generating scientific and health values rests on the greatest accumulation of data and biological samples possible. The assumption underlying the strive for quantity is that accumulation itself is useful for researchers by providing them with a lot of material ready to mine and with significant statistical power. In this respect, this biobanking configuration is characteristic of the data-driven paradigm of PH, where the accumulation of data is the primary goal (Hogle 2016).

6.2 Turning Accumulation into Waste

However, over time, critical voices among experts have pointed to the limitations of the logic of accumulation. Accumulation was initially valued because of its potential for producing scientific knowledge, but without any research project exploiting these data, the value of samples diminished: “I mean, all these samples, because they do not all have their DNA, and the buffy coat, one knows that after two or three years, or even five, it is not that good any more. One needs to extract the DNA and then it is stable. But it is a disaster if it takes too much time. It is a waste. [...] It is a sample cemetery, whose quality deteriorates day after day, and it is such a shame” (Biobanker 3, interview 14.03 2017). Here, time turns accumulation into waste and decreases the potential productivity of samples, if they are unused or not transformed into a more stable or durable form, such as DNA (Stevens 2016).

Moving from a revolutionary innovation and tool at the service of biomedical research at the moment of its creation, the hospital-based biobank has, over time, reverted to being part of the invisible infrastructure of the hospital. Its name itself has disappeared and been changed, and turned into an appellation valorizing biological samples and data, and not the biobank. In this way, the potential biovalue of samples and data is spotlighted, rather than the instrument of collection and storage. If, initially, the institutional unit of the university hospital was thought of by the researcher-biobanker team as an unproblematic reservoir for inpatients, and thus for the collection of data and samples, it has proven to be rougher than expected. Indeed, the biobank team ended up transforming

the modalities of recruitment and had to stop using data in research in order to face political and institutional demands to meet the standards of the Taipei Declaration regarding the return of research results, incidental findings, and patients' rights (WMA 2016), and integrate them into the governance of the biobank. In order to understand the difficulties met by this hospital-based biobank, we need to examine how participation has been enacted and has shifted over time.

7. Constituting a Public: Between Bioprovision and the Production of Collective Identity

In the cohort biobanking configuration, the boundary between research and healthcare is crossed when the results of research investigations feed immediately into clinical intervention, and when the space of research consultations becomes a place where people may feel cared for, in the sense of listened to and taken into account, but not in regard to genomic biomarkers. Rather, it is reconfigured in a way that draws a distinction between biological results of relevance for the clinic in the present and genetic findings tainted with the uncertainty inherent to the future of research progress and the complexity of understanding the genome. "Clinical and research sequencing are not the same in technical terms," explained our interlocutor and "we need to be very cautious about it" (Researcher 2, interview 09/02/2017). In this biobank configuration, maintaining a clear distinction between research and healthcare goals and techniques works as a way of leaving the uncertainty associated with the use of future research results in prevention and treatment, in the hands of researchers. This also provides them with the space and time for developing research without being concerned by returning genomic results to participants and questioning the social and ethical issues this may raise.

Interestingly, this configuration has not involved any formal public participation in governance so far. The cohort's population is not part of the governance committee of the study, is not consulted to give its opinion on issues which might be relevant for them, and has not expressed any demand for it either. In the expert's eyes, the strength of the collective identity generated through the "personalization" of the care for the cohort's population, which is identified with their city, replaced the need for a more institutionalized form of participation. This gave researchers the feeling that they engaged with their participants and took them into account, while enabling them to pursue their research activities without what is considered as the time- and resource-consuming burden of formal public participation strategies. However, due to the researchers' apprehensions regarding the reconfiguration of the research-healthcare interface and in order to meet the European standards for governance in biomedical research necessary to keep the cohort funded, a formalization of public participation is considered in the next follow-up phase of the

study (Researcher 2, interview 09/02/2017). While a rather clear temporal and practical distinction between the two domains has been maintained since the beginning of the study, the idealized vision of participation it enacted is challenged by these new prospects. Indeed, the form of collective identity constituted through the cohort population's bioprovision seems to lose its foundation with the transformation of the research-healthcare interface, opening up a space for the constitution of a public whose basis and common identity are open questions for the researchers, who are worried about how to construct it.

7.1 Providing, Donating or Advising?

In the general biobank, political and institutional demands for formal public participation strategies also played a role in the constitution of the biobank's public. During the first years of the hospital-based biobank, participating in the biobank was understood as a safe and unproblematic technical act – providing a blood sample taken during hospital routines – and signing a broad consent for it to be used for further research. During this first phase, the collection of samples was a primary goal and participation only considered as a form of bioprovision, supplying the biobank with samples. However, in the meantime, the notion of broad consent has started stirring controversy beyond the walls of the hospital, casting a shadow over this form of passive participation. At stake is the impossibility of completely severing the link between the biosamples, associated health-related data and the people they come from, in this case the inpatients. In addition, the complementary possibility of returning research genomic results and incidental findings, which might be of relevance for the clinic, was also considered problematic (Barazzetti et al. 2017).

In an attempt to respond to the critiques regarding the use of broad consent, stemming from both public health experts and patients' associations (Dessibourg 2017; Leroy 2017), bioprovision was then recast in terms of a donation to research by the biobankers' team. Intended to valorize inpatients' participation, it indicates a shift from a technical understanding of participation to a moral one: "The idea is to focus on donation in the sense of solidarity, of a collective engagement for a cause: scientific research, which is a marvellous thing and serves the common good, and thus the population. Research cannot advance without donations and the goal is to sensitize the population. Perhaps they don't know how to contribute in general, but they can participate philanthropically in research, they can donate their samples" (Biobanker 2, interview 28.02.2017). Turning to a rhetoric of solidarity – donation – for the promotion of biomedical endeavour (Aguzzi 2017) – which from these biobankers' perspective represents a common good in itself, turns the providers of biobanking samples into an altruistic and acritical population, sharing with the researchers the optimistic and idealistic vision of bio-

medical research as an enterprise which is worth donating and will ultimately benefit the whole society.

This tends to erase the economical dimension of research, as well as the exact nature of what can be given back to these participants. Instead of providing research participants with health benefits directly in the present, as was the case in the cohort biobank, here participants are expected to participate in the name of the promissory future of progress in biomedical research, without asking about the possible benefits biomedical research might bring to them or to society. This rhetoric masks the fact that potential clinical and preventive applications might be minor, are very uncertain and distant in time. Instead, it points to the importance of moving beyond the individual benefits one might draw from participation in the present, to contribute to the “common good” of research. In this way, it places participation in a moral economy based on a social contract of solidarity, which silences the issues raised by the reconfiguration of the research-healthcare boundary at stake in biobanking practices when they are put to the service of PH.

Framing participation in terms of donation for research was meant to address the external critiques concerning broad consent and issues raised by the blurring of the research-healthcare boundary in an attempt to publicly revalorize the biobank as an enterprise. Trying to constitute an external public with the idea that they could ideally be turned into the biobank’s population and provide samples, through a rhetoric of donation, the biobank’s team organized an open-door event centred around “donation for research” (Event 10/06/2018), but it remained unattended by the general public and the cautious actors, who had encouraged the biobank’s team to give greater consideration to the concerns of citizens and patients. The difficulty the biobank team encountered when trying to constitute a public, which was initially thought of as passive, trusting, and donating, led to an internal reorganization of the biobank and prompted researchers and biobankers promoting PH and who needed the biobank, to develop more formal attempts of “public participation”. To do so, they turned to the biobank’s bioproviders, in order to ask them about their opinions and preferences regarding the issues broad consent and the return of results. This turned the inpatients’ population, which until then had not been characterized or well identified, either by a specific disease or by some genetic, cultural, socioeconomic characteristics or an administrative/geographic unit, into a public, sharing a kind of sociality, as the enthusiastic and repeated involvement in the consultancy focus groups we organized with the biobank team indicates.

This public is expected to help the researchers’ team to address the uncertainties associated with the sensitive issues raised by the circulation of data and biomarkers and to orient future governance and practices in response to the critiques blaming them for ignoring social, legal and ethical issues. Whereas the issues raised by the porosity of the boundary between research and healthcare opens up a space where a need to consti-

tute a public emerges, which might in turn influence its reconfiguration process, it also enables researchers to go on with their scientific activities and to continue recruiting and enlarge the number of bioproviders. In a way, the constitution of this public, allows them to redefine the field of their expertise based on the technological and scientific dimensions and responds to external critiques and political demands, while leaving to the public the responsibility of deciding how they want data and research results to circulate between research and healthcare.

8. Conclusion

What is participation in emerging biobanking configurations in Switzerland? And how does this specific case illuminate the entanglements between identity and participation? This question stemmed from our observations about the recent local blooming of discourses and practices of participation in PH endeavours and the many different realities this umbrella term conveyed. In order to tackle this question and contribute to the understanding of the co-production dynamics of identity between biobanking and its participants, we focused on two contrasted biobanking configurations and explored the perspective of biobank operators and researchers. One is an epidemiological longitudinal cohort biobank centred around specific phenotypes and diseases, while the other is a prospective hospital-based general biobank. In both configurations, the modalities of participation determine the possibility for scientific, and ultimately health, values to be produced. Our analysis of the researchers' perspective working in the first biobank indicates that a form of collective identity is constituted through the sustained participation of the population and its identification to the city. According to them, the sense of community created through the population's participation in the cohort, which provides the reservoir for recruitment, also serves the production of scientific value as it contributes to increase the quality of data, necessary for research. Researchers consider that the form of personalized research care they provide and the sense of contributing to the common good of their city, for the sake of the health of future generations, work as a counter-gift for the participation of the population, in a way close the practical reciprocity described by Busby (2004) and Wadmann and Hoyer (2014). The second configuration, in contrast, is not focused on specific diseases. Based on a logic of accumulation proper to a data-driven paradigm, it aims rather at collecting the greatest number of samples and health-related data, assuming that the quantity will increase the potential scientific productivity of samples. Its population consists of inpatients, but has no well-defined identity and is rather initially reduced to a bioprovision role.

In the promissory discourses of participatory medicine advocates, the Swiss population's daily lives are turned into a reservoir for genomic and

other health-related data for the sake of biomedical research, and in exchange for data protection. In addition, the population seems to collide with the public, as Swiss citizens are also expected to give their opinion on the important issues raised by biobanking in PH. These discourses contribute in this way to shape an ideal figure of participant as morally attuned, caring for future generations, concerned by the common good, and engaging democratically in public debates. In other words, being a good citizen means participating in biobanking both as a bioproducer and as part of the public. This ideal figure is very much aligned with the need for health-related and genomic data, solidarity and trust, necessary to the development of PH. In contrast, in the two biobanking configurations examined, the reconfiguration of the research/healthcare interface characterizing the move to the data-driven paradigm of PH, is very much present and at the core of shifting enactments of participation.

In the cohort configuration, the collective identity, generated through the population's enrolment, works as a substitute for formal public participation in the governance of research, allowing researchers to avoid what they consider as a time- and resource consuming activity out of the scope of their field of expertise, while giving them the sense of caring for their population. However, the prospect of having to deal with issues raised by the return of results and incidental findings, as well as the call for participatory governance from the funders to meet EU standards, challenge this idealized version of participation, in which researchers and participants are apparently both satisfied by maintaining a boundary between research and healthcare leaving an open ground for the constitution of a public whose shape remains to be defined.

In the general biobank too, the role of participants as simple bioproducers is challenged by the need to keep a traceable connection between the identity of the inpatients supplying the biobank and the biological samples for the purpose of research, but also in order to return possibly relevant incidental findings and research results. In a first phase, bioproducers were requalified as donors for research, in an attempt to increase the public legitimacy of the biobank's activities and goals, and respond to external critiques around broad consent. The underlying assumption was that valorising donation would increase the mass of the population of bioproducers by turning them into a passive and trusting public. However, this altruistic rhetoric remained unable to meet the challenges raised by the reconfiguration of the boundary between research and healthcare. It is only through the transformation of the inpatients' population into a public, consulted about its opinion and preferences regarding the return of results, that another form of collective identity as public started to take shape.

Does the collective identity constructed by biobankers leave room for the agency of participants or are the public and/or population passive collectives enrolled for the sake of biovalue production? Our analysis shows that the constitution of a biobank public allows researchers to pur-

sue their research activities by delegating the work and moral responsibility of the social and ethical implications raised by the blurring of the boundary between research and healthcare to its public, without questioning the epistemological and political distinction underlying it. As a consequence, while this reconfiguration generates a possibility for doing research *with* patients, to go back to the Dean's introductory expression, opening up a space for a new kind of relationship between researchers and the biobank's population and public, it also seems to reinforce the boundary and hierarchy between the technical and epistemological goals of research left in the hands of experts and the responsibility for ethical and social issues raised by the increased circulation of samples and data, which is delegated to the public.

Our analysis of the overlaps between the population of bioproviders and the public which is engaged in participatory governance, as one replaces or is transformed into the other, indicates also that the production of a collective identity plays an essential role in the implementation of formal strategies of participatory governance, and seems to be necessary for the continuation of biomedical research, both in terms of tissue provision and in terms of increased legitimacy. In our case, this collective identity is not based on shared genetics or common past history, but is constituted through participation in biobanking, as population or as public. The specific conflation of research and healthcare on the one hand and of population and public on the other shapes an ideal figure of a biocitizen. While the constitution of this figure might be used for the benefits of PH research, we suggest, that it might also provide the participants with the conceptual and symbolic tools and space, through which other forms of agency and collective identity might unfold. At the present moment, instead of representing a threat, it seems that some biobankers welcome this more active form of participation, aligned with the ideal of the biocitizen providing samples *and* contributing to biobanking governance, as long as it remains compatible with the biobanking enterprise and increase the production of biovalue. Whether, this model will be actively appropriated by participants and lead to other forms of resistance, contestation and identity remains an open question, that only future exploration of PH in Switzerland will be able to answer.

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¹ A notable exception is the technology assessment procedures initiated by the federal foundation TA-swiss and involving public participation strategies such as consensus conferences. For more information see: <https://www.ta-swiss.ch/> (accessed 02/10/2018).

² <https://www.leenaards.ch/interdomaines/sante-personnalisee-societe> (accessed 29/07/18).

³ <https://www.planetesante.ch/salon> (accessed 29/07/18).

⁴ <https://www.santeperso.ch/Agenda/Bien-vieillir-au-21eme-siecle-la-sante-personnalisee-au-service-des-seniors> (accessed 29/07/18).

⁵ About 70 500 000 US dollars or 60 000 000 Euros.

⁶ <https://www.sphn.ch/en.html> (accessed 29/07/18).

⁷ *Health 2030* benefits from the burgeoning innovative high-tech health sector situated in the Lake Geneva region of Switzerland (Genier 2017) and contributed to the opening of the first Swiss Genome Center in May 2017. For more information see: <https://health2030.ch> (accessed on 22/10/2018).

⁸ <https://swissbiobanking.ch/> (accessed 29/07/18).

⁹ While experts speak of personalized health and medicine, the reference is often made to the '4P medicine', which is Predictive, Preventive, Personalized and Participatory (Auffray et al. 2010).

¹⁰ For more information on genome wide associations, look at <https://www.genome.gov/20019523/genomewide-association-studies-fact-sheet/> (accessed 30/07/2018).